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AUTHOR Williams, Dennis
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ABSTRACT

Although denial is usually viewed as a mechanism which impedes a family's adjusting to a child's permanent disability, the mechanism may also be viewed as a family ally which contributes to recovery and positive outcomes in brain-injured children. This paper reviews several types of denial seen in clinical settings and provides examples of both positive and negative features of this complex mechanism. The paper begins with a case study of a 25-year-old, single mother whose 8-year-old son suffered a severe head injury. Some of the clinical manifestations of denial in this case and others include nonrecognition of the child's condition, guilt, refusal to accept professional predictions for less than complete recovery, and the display of courage or the brave front. Except for the denial from guilt, it is argued that all of these manifestations of denial may provide both parent and child encouragement and support. Such support is deemed important in the struggle for the appropriate treatment of a condition which often requires life-long care. However, since denial must be managed, the paper offers suggestions on how to recognize the context of denial, as well as recommendations on how that denial can be structured. (RJM)

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Parental Denial: a supportive and productive mechanism following traumatic brain injury of a child

Dennis Williams, PhD
257 Regents Blvd
Fircrest, Washington 98466
(206) 565-6098

Although denial is usually viewed as a mechanism which impedes a family's coming to terms with adjustment to a child's permanent disability following brain injury, the mechanism may also be viewed as a family ally which contributes to recovery and positive outcome in brain injured children. This paper will review several types of denial seen in clinical settings, and provide examples of both positive and negative features of this complex mechanism.

Illustrative Case

Robbie is the only child of a 25 year old single woman. At age 8, he was struck by a car on his way home from school. He sustained multiple traumatic injuries, including severe closed head injury with subdural hematoma, brain contusion, and brain swelling accompanied by prolonged increased intracranial pressure. His mother was informed by the neurosurgeon at the trauma center that his chances of survival were slight.

Robbie's mother took up a vigil beside her son's bed, aiding nurses in his personal care, reading to him, and talking to him about pleasant past experiences. At night, when the intensive care unit was quiet except for the monotonous sounds of life-sustaining equipment, she would sit in the dark and hold his hand, thinking about all the times she had been angry with him for little things, and she would promise that she would be a better mother if God would let him live.

Over three days, the intracranial pressure gradually subsided, but Robbie remained deeply comatose. The neurosurgeon told her that he might never recover from coma. But even if he did recover, the injury to his brain had been massive, and he would probably remain severely impaired.

Robbie's mother stayed at his bedside throughout a three-week coma. She slept in short stretches, and her sleep was often interrupted by dreams of Robbie calling to her to help him. She would waken with a start and listen intently, but only hear the sounds of machines and of the nursing staff carrying out routines of care. Then one day, while she was washing his face, Robbie turned his head away and reached out slowly in an effort to stop her.

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From that point, he began to show more consistent purposeful movement. He was transferred to a rehabilitation unit. Two days later, he was up in a wheelchair, smiling appropriately when she tickled him. Although medically, he was still significantly impaired, moving little without assistance and without intelligible speech, Robbie's mother could see daily improvements in his response to her presence and to her play with him. He was definitely getting better.

Over the next four weeks, Robbie received intensive speech and physical therapies. His mother helped to feed and clean him. He would vocalize his discomfort at attempts to wipe his face and pull away. At times, when she read to him, he would laugh just as he used to laugh when she would play with him as an infant. Old friends and relatives visited Robbie often. His mother made new friends of other parents during that time, and saw other children recover from comas. Several children were walking and talking after a few days.

As time passed, children who seemed as badly hurt as Robbie were being discharged to their homes with plans to re-enter school. But Robbie was still not speaking intelligibly, nor was he able to move without considerable help. Her newly made friends began to leave with their children. Old friends and relatives visited less frequently. Nurses and other rehabilitation staff reminded her that all injuries were different, and that recovery rates were not the same for all children. In spite of their encouraging words, however, she noticed subtle changes in their attentiveness to Robbie and a tendency to answer her questions about her son's progress with less optimistic assurances.

At the end of six weeks, she was told by the rehabilitation physician that Robbie seemed to have plateaued--he was not showing measurable gains from intensive inpatient treatment, and would be discharged from the hospital with plans for therapy on an outpatient basis. She sat quietly as the physician explained the findings of the most recent brain scan--enlarged ventricles, subcortical damage--without really listening past the practiced sympathy and clinical sounds of the carefully chosen words. She thanked the doctor and left his office feeling empty and numb.

As she walked down the hall, she thought of the headline articles she had seen which had proclaimed miracle recoveries after years of coma, of new treatments which could mend damaged brain tissue. She remembered the grave predictions of the neurosurgeon and of others during the first few days after Robbie's injury. The words of the rehabilitation doctor were just another expression of cold, professional resignation--professional abandonment. She would never do that to her son. She would never give in to discouragement.

On the way back to her son's room, she stopped at a rest room. Locking the door behind her, she stood at the sink for several seconds, tears filling her eyes and running down her face, dropping onto the pristine surface of the porcelain. Without looking at her reflection in the mirror, she let water run into her hands and bathed her face slowly. She would not let her son or anyone else see her that way, full of anger...full of a sense of hopelessness and grief.

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In Many ways, Robbie's mother's experiences are typical of parents whose children are tragically and permanently injured. Her reaction, one of grim determination not to give in to her overwhelming sense of hopelessness is also typical. Denial of family members is a well-known and troublesome phenomenon. Parents who are "in denial" after a child has sustained traumatic brain injury may interfere with appropriate rehabilitation treatments, and may not follow through with discharge plans for continuation of therapies through community based services.

Some Clinical Manifestations of Denial

1. Nonrecognition of the child's condition.

   The parents focus on recognition of preinjury characteristics in their child. Small, familiar, usually automatic, verbal or physical mannerisms are noted and interpreted as signs that their child is there, regardless of surface appearances.

2. Guilt.

   Denial behaviors driven by guilt may be displayed in the belief that loving parents should be able to recognize their child through physical and behavioral disfigurement. Such denial is fostered by a sense of decorum--what a loving parent is expected to do under the circumstances. Guilt driven denial may also reflect the feeling of many (if not all) parents that they have somehow failed to protect their child from dangers which they should have anticipated.

3. Refusal to accept professional predictions for less than complete recovery.

In this case, parents recognize the child's immediate situation, but view it as temporary. This kind of denial is supported by the family's past experiences (survival from life threatening injury, recovery from initial comatose state, subsequent neurologic gains). Such denial is also supported by models of good outcome which are seen by the family (other children who have recovered from traumatic brain injury or stories they have heard about recovery), by optimistic assurances of hospital staff, and by hope.

4. Courage or the Brave Front.

Parents may believe that it is necessary for the good of their child to portray a picture of confidence and hope. They do this in the face of recognition of the severity of their youngster's condition and with the sense that their behavior will, at least temporarily, spare the child from having to face the terrible truth about his or her injury. In addition, parents who put on a brave front hope that their behavior will sustain the recovery efforts of their child, motivating the youngster to work hard in therapies.

Another purpose for courage in the face of severe injury is to sustain professionals. Parents may fear that professionals who do not see gains in function after intensive interventions will reduce services or discontinue therapies because of discouragement. This is not an altogether unwarranted fear on the part of parents, since treatments tend to be less aggressively applied when providers cannot justify treatment by demonstrating therapeutic efficacy. Parents often perceive therapeutic "step-downs" as giving up on the child, and desperately encourage continuation of maximum service delivery.

Except, perhaps, for denial which is manifested from guilt, all of these manifestations of denial may have utility in that they can provide encouragement and support for persistent advocacy for appropriate treatment of a condition which often requires life-long care. However, all forms of denial need to be carefully managed to prevent them from becoming nonproductive or obstructive.

Managing Denial

A first step in the management of denial is to gain some appreciation for the perspective of the family. Professionals need to understand that, for the family, the road to recovery is littered with the debris of shattered hopes and dreams. Travel down that road is relentless; filled with new and unexpected obstacles. Families are forced to be there; forced to deal with strangers who may interfere with life as they wish it could be; forced to be subjected to clinical scrutiny by persons who are not always sensitive to their feelings.

The clinical professional must appreciate the long-term nature of the recovery process, both from a physical/ cognitive standpoint and from a psychosocial/adjustment standpoint. In children, because the complex processes of physical, cognitive, and social development are interacting with changes in normal function resulting from injury, the course of recovery is not predictable. What may be predicted is that major changes in internal systems (onset of puberty) and major changes in environmental or social demands (entry into middle/junior high school) will result in renewed stresses on marginal cognitive systems and fragile coping mechanisms. Resultant problems with adjustment will again confront families with situations which throw them back on hope and faith.

Additionally, there are late onset post-traumatic medical complications which may be experienced by a relatively large number of families: hydrocephalus and seizures are most common, but other issues may arise such as diabetes and other organ system dysfunctions.

Finally, it is important to understand that Denial does not need to be "dealt with" in a final sense. It is a natural phenomenon with associations to faith and hope, two human qualities which exist to confront harsh reality, and which become strongest in the face of the grimmest facts. For this reason, the clinician should expect denial to be a long-term and more or less active component of family behavior and endeavor to manage denial by acknowledging its legitimacy. Family members need assurances that their feelings concerning their child are understandable.

Management Recommendations

A. Approaches to managing denial may include helping the family to recognize differences between long term outcomes and current therapeutic needs necessitated by the immediate situation. One way to do this is to stress the idea that recovery is a long-term process, one that has a number of phases: beginning in the hospital emergency room and moving from there to the operating

room, ICU, acute care hospital setting, out-patient hospital-based therapy setting, home care, school, and community settings. Each phase has its own set of difficulties requiring adjustment; each phase has its own set of promises and disappointments.

B. Families will benefit from having information about head injury which reflects state-of-the-art clinical knowledge. Information about experimental treatments which have not been validated by successes in clinical trials may do more harm than good. Professionals need to keep abreast of research and should have contact with reputable area resources which can provide answers to family questions about scientific "miracle breakthroughs" reported by the popular press or communicated by word-of-mouth by other parents or by well-meaning individuals who are unfamiliar with traumatic brain injury.

C. Setting arbitrary time lines for recovery (ie, 6 months, a year) is adopted by some professionals as a device to "buy time" in the belief that, as time passes, the family will learn to accept the obvious. The risk in this lies in the tendency for families to focus all of their hopes on some specific point in time where the injured child will be restored. This is likely to result in disappointment, loss of a family's faith in professionals, and ultimately in the family removing the child from the care system entirely.

D. Families may benefit from contact with other families who have children with brain injuries. Group sessions where information about TBI may be presented, or self-guided parent support groups may be helpful. Ideally, members of the group should be mixed, with some group members having had long-term experience with having a child with TBI and others whose children have been more recently injured. A mixture of this nature allows families to draw on one another's experiences.

E. Families need to be educated about the potentials of their child to experience life normally, as well as be given realistic predictions for the child's ultimate life achievement. Providing education about the nature of TBI and its physical, cognitive, and socioemotional consequences may be helpful. Parents who believe their child to be irrevocably lost to them will need to be educated to the child's change and his or her need for support.

F. Many parents will need help to deal with their anger and resentment over their loss. They must deal with their sense that their child was (or is) perceived as a burden

or a trial. They must also eventually deal with the guilt associated with their sense that they have abandoned their preinjury child (or their hurt at having been abandoned by their child).

G. Keep in periodic contact with the family. Yearly contact after the family has been provided with information and has been served or referred appropriately may be enough to let parents know that someone is concerned and recognizes that the family's vigilance for change continues. Periodic contact frequently reveals child and family needs which might not be addressed unless the potential for voice-to-voice or face-to-face interaction exists.

RECOMMENDED READING

Batshaw, M., Perret, Y., and Trachtenberg, S. (1992). Caring and coping, the family of a child with disabilities. In: M. Batshaw and Y. Perret, Children with disabilities: a medical primer. Baltimore, MD: Paul H. Brooks Publishing Co., 563-578.

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